NAMI Kansas
National Alliance on Mental Illness

March 7, 2011

Medicaid Reform: Items for Consideration

1. Medicaid resources should be applied to the most effective services, ideally those evidence-based practices which also have proven to be cost-effective.
    a. See the attached slides on the array of services for adults and children which represents the necessary continuum of care.
    b. Medicaid should pay for services that fall outside the traditional medical model. Specifically, rehab services are cost effective for those whose illnesses are more severe.
    c. The parameters of a high quality mental health system are addressed in the attached files from the 2009 Grading the States report. We can provide a full copy of the report upon request.
2. Maintain the current statutory exemption from the preferred drug list for psychiatric medications. Psychiatric medications are central to most treatment plans. An appropriate range of medications must be available to patients based on their individual needs and tolerances. A "one size fits all" system will result in costly consequences for individuals and communities. See attached issue paper on the Preferred Drug List.
    a. Concerns about issues related to poly-pharmacy should be addressed through a disease management model and through the adoption of systems for monitoring prescribing patterns of individual providers.

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NAMI
National Alliance on Mental Illness

State Advocacy

Adult Array of Services

Mild Mental Illness	Moderate Mental Illness	Severe/Acute Mental Illness

Uniform screening and assessment

Effective therapies

Peer services and supports

Medications

Integrated psychiatric and physical health care

Psychoeducation for individuals and families

Case management/Integrated plan of care

Illness Management & Recovery/WRAP

Integrated Dual Diagnosis Treatment

Supported Employment

Permanent Supportive Housing

Assertive Community Treatment

Jail diversion

Crisis intervention & stabilization

Acute and long term care

(A sampling of the array of services needed in a community system of care)

NAMI
National Alliance on Mental Illness

State Advocacy

Child and Youth Array of Services

Mild Mental Health Condition	Moderate Mental Health Condition	Severe/Acute Mental Health Condition

Uniform screening and assessment

Effective therapies (e.g. Cognitive Behavioral Therapy, Brief Strategic Family Therapy)

Peer services and supports

Medications

Integrated psychiatric and physical health care

Psychoeducation for families

Care coordination/Wraparound planning

School and in-home behavioral supports

Wraparound integrated planning and services

Intensive evidence-based interventions*

Integrated dual diagnosis treatment

Juvenile justice diversion

Crisis intervention & stabilization

Acute and longer term care

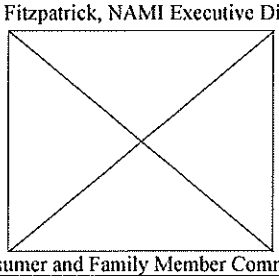
* There are multiple evidence-based interventions and promising practices for various age groups and symptoms. Three well-known models are **Functional Family Therapy (FFT), Multisystemic Therapy (MST)** and **Multidimensional Treatment Foster Care.**

A Report on America's Health Care System for Adults with Serious Mental Illness
About NAMI - Grading the States 2006 - Your Local NAMI - Donate - FAQ

Grading the States 2009: A Report on America's Health Care Sytem for Adults with Serious Mental Illness

NAMI's Recommendations for States and the Federal Government

Mike Fitzpatrick, NAMI Executive Director



Consumer and Family Member Comments

view photos from Grading the States

1. Increase Public Funding for Mental Health Care Services

Where We're Failing

Adequate funding for mental health has long been a low priority for states:

- Although Medicaid spending has increased, non-Medicaid state spending has not kept pace.
- Growth in state mental health spending is slower than total growth in state government expenditures.
- As the national economic crisis worsens, many states are making-or considering-even greater cuts to mental health services.

Taking Action

During difficult economic times, wise choices on spending must be made. Cuts to state mental health services are unwise because they inevitably lead to greater costs in other areas. States truly committed to investing in recovery should increase funding of public mental health services, while making sure that these funds are spent wisely on services that work.

In addition to state general funds, states across the country are finding creative and successful ways to generate new revenues or reconfigure existing resources to increase funding for mental health services.

Institute Modest Tax Increases

- California's Mental Health Services Act authorizes the state to levy a one percent tax on annual personal income exceeding $1 million. Funds are used to develop and implement innovative mental health services in the community.
- Counties in Washington are authorized to impose a sales tax add-on of one-tenth of one percent to fund new mental health, chemical dependency, or therapeutic court services at the local level.
- States such as Arkansas, Florida, Kentucky, North Carolina, and South Carolina, among others, are considering increases in taxes on cigarettes or alcohol (i.e., "sin taxes"). Revenues could be targeted to mental health funding, including smoking cessation programs and other similar interventions.

Reallocate Resources

- Connecticut and Florida reinvest dollars from their criminal justice systems into community based services, housing for ex-offenders (including those with serious mental illnesses), jail diversion, and mental health services.
- Kentucky finances an innovative jail mental health triage program through revenues generated from court costs and fees.

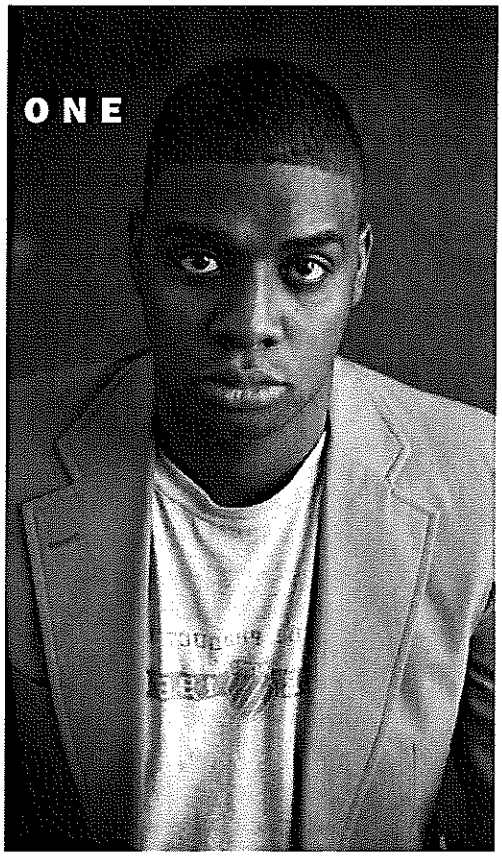
Establish Dedicated Trusts

- Alaska established a trust in perpetuity to fund systems improvement and innovative programs for people with mental illnesses. The trust is financed through one million acres of land managed by the state to generate income to help pay for a comprehensive, integrated mental health program.
- Oregon created a housing trust fund for people with mental illnesses through revenues generated from the sale of a state hospital.

Continue to recommendation 2: Improve data collection, outcomes measurement, and accountability >>

"Recovery is regaining or developing the abilities one needs to reclaim a constructive place in society in spite of being diagnosed with a severe and persistent mental illness."

CHAPTER ONE



A Vision for Transforming State Public Mental Health Systems

In 2003, the presidential New Freedom Commission described mental health care in the United States as a "system in shambles," in need of fundamental transformation.[1] Three years later, in another major report, the National Academy of Sciences' Institute of Medicine (IOM) proposed a major overhaul of our behavioral health care system, calling it "untimely, inefficient, inequitable, and at times unsafe."[2] These findings built on the U.S. Surgeon General's landmark 1999 *Report on Mental Health*.[3] Yet despite these repeated calls for reform, the prospects for people with serious mental illnesses in this country remain bleak.[4]

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[1] New Freedom Commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America: Final Report* (Rockville, MD: DHHS Publication No. SMA-03-3832, 2003). Available at http://www.mentalhealthcommission.gov/. These findings echo earlier assessments of the nation's public mental health system including the work of Dorothea Dix in the 1800s, Albert Deutsch in the 1940s, and E. Fuller Torrey in the 1980s and 1990s.

[2] National Academy of Sciences Institute of Medicine (IOM), *Improving the Quality of Health Care for Mental and Substance-Use Conditions: Quality Chasm Series, Committee on Crossing the Quality Chasm: Adaptation to Mental Health and Addictive Disorders* (Washington, DC: The National Academies Press, 2006). Available at http://www.iom.edu/CMS/3809/19405/30836.aspx. "Behavioral health" is a term that encompasses the diagnosis and treatment of both mental illnesses and/or substance abuse disorders.

[3] U.S. Department of Health and Human Services, *Mental Health: A Report of the Surgeon General* (Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health, 1999). Available at http://mentalhealth.samhsa.gov/cmhs/surgeongeneral/surgeongeneralrpt.asp.

[4] NAMI identifies as a priority population those persons of all ages who have serious mental illnesses including schizophrenia, schizoaffective disorder, bipolar disorder, major depressive disorder, obsessive-compulsive disorder, panic and other severe anxiety disorders, borderline personality disorder, post-traumatic stress disorder (PTSD), autism and pervasive developmental disorders, and attention deficit/hyperactivity disorder. These disorders represent the major mental disorders that current scientific data and consensus conclude are identifiable, disabling medical illnesses, with significant biological underpinnings, and requiring treatment.

The nation can sit idly no longer. It is time to break down the barriers in government that have led to the abandonment of people with serious mental illness; and to undo years of bad policies that have increased the burdens on emergency rooms, the criminal justice system, families, and others who have been left to respond to people in crisis. We must invest adequate resources in mental health services *that work* and finally end the pervasive fragmentation in America's system of care.

A transformed mental health system would be comprehensive, built on solid scientific evidence, focused on wellness and recovery, and centered around people living with mental illnesses and their families. It would be inclusive, reaching underserved areas and neglected communities, and fully integrated into the nation's broader health care system.

A transformed system will require new attitudes and new investment. To reach this goal, we need vision and political will—on Capitol Hill, in state legislatures, and in communities across America. The good news: we know now what is necessary to create the mental health care system we want to see. Building on NAMI's *2006 Grading the States* report, this 2009 edition identifies the pillars of a high-quality system, provides an unvarnished assessment of where we are—state-by-state and as a nation—and identifies specific recommendations to guide the field towards the vision.

10 Pillars of a High-Quality State Mental Health System

As a nation, and as a mental health community, our knowledge base about mental illness is uneven. We know far less than we should about the causes and courses of mental illnesses. On the other hand, we know a lot about the staggering consequences—for the individual, for families, and for society—of untreated mental illness. We know that we provide treatments and services too late, and that too few people get the help they need to experience recovery. We also know that in order to deliver effective treatments to the many people who need them, public mental health service systems need to change dramatically.

Based on what we know, derived from 30 years of research and work in the field, NAMI understands what a successful mental health system must include. NAMI believes deeply that a transformed mental health system has the following very specific characteristics. It is:

1. Comprehensive;
2. Integrated;
3. Adequately funded;
4. Focused on wellness and recovery;
5. Safe and respectful;
6. Accessible;
7. Culturally competent;
8. Consumer-centered and consumer- and family-driven;
9. Well-staffed and trained; and
10. Transparent and accountable.

These are the 10 pillars of a high-quality mental health system. Following is a brief discussion of each one—why it is critical and where things stand (a more detailed, state-by-state analysis can be found in Chapter 5). The sections below also provide some strategies states can pursue to begin addressing the challenges in each area.

1. Providing Comprehensive Services and Supports

Today, having a serious mental illness need no longer mean a lifetime of suffering or dependency. Indeed, many people living with mental illnesses, and their families, often describe themselves as being in "recovery," meaning they are, or are working toward, living independently in a community of their choice, while striving to achieve their full potential.[5] For many, this goal is realistic if the right services and supports are in place. Throughout this report, we include direct quotes about recovery from people living with serious mental illnesses and their family members.

[5] This definition was developed at a National Consensus Conference on Mental Health Recovery and Mental Health Systems Transformation on December 16-17, 2004. As part of this conference, a series of technical papers and reports were commissioned examining topics such as recovery across the lifespan, definitions of recovery, recovery in cultural contexts, the intersection of mental health and addictions recovery, and the application of recovery at individual, family, community, provider, organizational, and systems levels. Substance Abuse and Mental Health Services Administration's (SAMHSA) National Mental Health Information Center: Center for Mental Health Services, *National Consensus Statement on Mental Health Recovery* (Washington, DC: U.S. Department of Health and Human Services, 2004). Available at http://mentalhealth.samhsa.gov/publications/allpubs/sma05-4129/.

Every mental health system must have carefully balanced and adequate levels of care. The service continuum includes state hospitals, short-term acute inpatient and intermediate care facilities, crisis services, outpatient and community-based services, and independent living options. The exact mix and intensity of necessary services will vary from one person to another, and even for the same person, over time. A truly comprehensive mental health system must offer, regardless of ability to pay, services such as:

- Access to prescribers and medications;
- Acute and long-term care treatment;
- Affordable and supportive housing;
- Assertive Community Treatment (ACT);
- Consumer education and illness self-management;
- Crisis intervention and stabilization services;
- Family education;
- Integrated treatment of co-occurring disorders;
- Jail diversion;
- Peer services and supports; and
- Supported employment.

This list is not exhaustive. A comprehensive system would also include screening, assessment, and diagnosis; a wide range of diagnostic-specific therapies (e.g., Dialectical Behavior Therapy for borderline personality disorder); case management; psychosocial rehabilitation; certified clubhouses; drop-in centers; supported education, and many other critical services and supports. The list will grow and change as new scientific evidence identifies emerging, promising, and best practices. Brief descriptions of the service components listed above are found in a textbox towards the end of this chapter.

Services Should Be Evidence-Based

State mental health systems and other state agencies must ensure that the services and supports they deliver are *effective*. Treatments and approaches with proven effectiveness are growing and must be made available in every community that needs them, replacing outdated and less effective alternatives (see textbox on "Bridging Research and Practice").

"Recovery means that my mental illness is a part of my life instead of the focus."

— Consumer from Montana

More research must be conducted so that "promising practices" and treatments can be developed for sub-groups of people that lack well-established, effective approaches. As the lead federal agency for transformation initiatives that have flowed from the New Freedom Commission, the Substance Abuse and Mental Health Services Administration (SAMHSA) has played an important role in disseminating national guidelines and "implementation resource kits" for proven evidence-based practices (EBPs) such as ACT, supported employment, and inte-

Bridging Research and Practice

Many non-profit organizations and government agencies are helping disseminate up-to-date information about evidence-based practices (i.e., those that have been proven to consistently produce specific, intended results). These include:

- The federal Agency for Healthcare Research and Quality (AHRQ): http://www.ahrq.gov/clinic/epcindex.htm#psychiatry
- The American Psychiatric Association (APA). Practice Guidelines can be found at: http://www.psych.org/psych_pract/treatg/pg/prac_guide.cfm
- The American Psychological Association's Committee for the Advancement of Professional Practice's (CAPP) Task Force on Serious Mental Illness and Severe Emotional Disturbance (TFSMI/SED): http://www.apa.org/practice/grid.html
- The Centre for Evidence-Based Mental Health (CEBMH): http://www.cebmh.com/
- The Cochrane Collaboration: http://www.cochrane.org
- The National Guideline Clearinghouse. Diagnostic, assessment, and treatment guidelines can be found at: http://guideline.gov
- The Substance Abuse and Mental Health Services Administration (SAMHSA). Evidence-Based Practices Implementation Web site: http://ebp.networkofcare.org; Evidence-Based Practice (EBP) Implementation Resource Kits: http://mentalhealth.samhsa.gov/cmhs/CommunitySupport/toolkits/; and National Registry of Evidence-Based Programs and Practices (NREPP): www.nrepp.samhsa.gov
- The Technical Assistance Collaborative (TAC) and the American College of Mental Health Administration (ACMHA). A step-by-step manual, *Turning Knowledge into Practice: A Manual for Behavioral Health Administrators and Practitioners About Understanding and Implementing Evidence-Based Practices* (Fall 2003), can be found at: http://www.tacinc.org/Pubs/TKIP.htm

grated dual diagnosis treatment (IDDT). SAMHSA has also awarded Transformation State Incentive Grants (TSIGs) to nine states to accelerate improvements in their mental health infrastructure (e.g., inter-agency collaboration, technology use, and workforce development).[6] Together, these are meaningful first steps, but much more is needed.

[6] In October 2005, grants were awarded to Connecticut, Maryland, New Mexico, Ohio, Oklahoma, Texas, and Washington. In October 2006, two additional awards were made to Hawaii and Missouri. See http://mentalhealth.samhsa.gov/cmhs/CommunitySupport/mentalhealth/ default.asp.

Finding the Right Balance

Establishing the right balance of high-quality services means avoiding shortages on either end of the continuum of care. When a full spectrum of community-based services is not available, people languish in emergency rooms, hospital beds, jails, and nursing homes, and those facilities become overcrowded. As one commentator succinctly noted:

> The key to all this is a balance between adequate inpatient slots and a robust set of community services—a balance many states have had trouble striking, especially as they cut or fail to fund

Non-Adherence to Treatment

It is not uncommon for people with serious mental illnesses to discontinue their own treatment, in particular, their use of prescribed medications. There are a number of reasons for this:

- They have a neurological syndrome called Anosognosia that leaves them unaware that they are ill. As many as 50 percent of people with schizophrenia are affected by this condition,[7] and it is the most significant reason why people with illnesses characterized by psychosis refuse treatment;
- Their medications have uncomfortable or even debilitating side effects;
- They experience little or inadequate symptom relief;
- They perceive stigma about having a mental illness; and/or
- They have had negative experiences in the mental health system, ranging from indifference and disrespect to abusive and inhumane treatment.

What Are The Consequences?

The consequences of discontinuing treatment can be devastating, including unnecessary hospitalizations, homelessness, criminal justice involvement, victimization, and suicide.[8]

What Can Be Done?

Because of the very real potential for harmful or tragic consequences, mental health systems should have a range of strategies in place to help people with serious mental illnesses adhere to their prescribed treatment.

Assertive Community Treatment (ACT) — An evidence-based, outreach-oriented, service delivery model using a 24/7 multi-disciplinary clinical team approach, ACT provides comprehensive, individualized community treatment (including substance abuse treatment, housing, and employment support) and is particularly effective in helping people who are most at risk of falling through the cracks of the mental health system.

Peer Support — People who live with mental illness are often very effective in assisting or encouraging their peers to stick with treatment. Programs emphasizing self-help and mutual support have gained prominence in public mental health systems,[9] and anecdotal evidence suggests they should be studied further.

Motivational Approaches — Borrowing from the success of motivational approaches used to treat addictions, mental health-oriented techniques are emerging. For example, the LEAP (Listen-Emphasize-Agree-Partner) method has been shown to build trust, reduce conflict, and lead to positive outcomes over time.[10]

Respectful Treatment Environments — Environments in which people are treated with respect and dignity are important to forging trust,

(continued)

[7] Mark Olfson et al., "Awareness of Illness and Non-Adherence to Antipsychotic Medications Among Persons with Schizophrenia," *Psychiatric Services* 57 (2006): 205; and Stefano Pini et al., "Insight into Illness in Schizophrenia, Schizoaffective Disorder, and Mood Disorders with Psychotic Features," *American Journal of Psychiatry* 158 (2001): 122.

[8] A study of individuals with severe mental illnesses in the Los Angeles county jail revealed that 92 percent had a history of non-adherence to psychiatric medications prior to arrest. H. Richard Lamb et al., "Treatment Prospects for Persons with Severe Mental Illness in an Urban County Jail," *Psychiatric Services* 58, no. 6 (2007): 782. The Olfson et al (2006) study, cited above, also revealed that individuals with schizophrenia who discontinued psychiatric medications were more likely to be hospitalized.

[9] Ingrid D. Goldstrom et al., "National Estimates for Mental Health Mutual Support Groups, Self-Help Organizations, and Consumer-Operated Services," *Administration and Policy in Mental Health* 33, no. 1 (2006): 92.

[10] Christina Bruni, "An Interview with Xavier Amador, Ph.D.," *Schizophrenia Connection.com*, http://www.healthcentral.com/schizophrenia/c/120/27693/interview-part/pf/ (accessed on January 12, 2008).

Non-Adherence to Treatment *(continued)*

which then promotes adherence to treatment. When positive, respectful attitudes are conveyed by everyone from receptionists to treatment professionals, an individual's experience of treatment is greatly improved.

Psychiatric Advance Directives (PADs) – PADs are legal agreements through which people with mental illnesses can state treatment preferences and/or authorize others to act on their behalf if they cannot make informed decisions concerning treatment of their mental illness. Twenty-five states have laws authorizing PADs; in others, PADs may be part of living wills or general healthcare advance directives.

Conservatorships and Guardianships – All states have laws authorizing courts to appoint an individual to make treatment decisions for another individual who has been determined to lack capacity (i.e., competence) to make those decisions. These legal tools for substitute decision-making are time limited and last only as long as the person remains incompetent.

Assisted Outpatient Treatment (AOT), or Involuntary Outpatient Commitment – Assisted outpatient treatment laws authorize courts to order certain individuals to participate in community treatment. There are strong differences of opinion among mental health advocates and others about AOT. Proponents assert that it is humane and life-saving, while opponents argue that it is an egregious violation of individual rights. NAMI's position is that mental health systems should strongly emphasize strategies that promote voluntary participation, and use involuntary treatment as a last resort.

Forty-two states have laws authorizing AOT. Though many rarely use it, a few use it with regularity including Iowa, New York, North Carolina, and Wisconsin. Legal criteria for using AOT are very narrowly defined in virtually all states, court orders are time limited, and individuals have the right to free legal representation, to present testimony and witnesses on their own behalf, and to have their cases periodically reviewed, among other rights.

Studies suggest that AOT can produce positive outcomes when implemented properly. For example, it must be done in conjunction with sufficient and proven community-based treatment services.

AOT is not a solution for the inadequacies of the public mental health system. If effective and humane community mental health services were more widely available, involuntary interventions would be less necessary. However, experiences in states that use AOT suggest it is one tool that, when used judiciously, can make a positive difference.

> the community services that might keep people out of inpatient beds—all the while cutting the number of those beds.[11]

Another important consideration and challenge is that many people with serious mental illnesses do not seek treatment or follow through with treatment plans. The consequences of this can be devastating, from unnecessary hospitalizations or homelessness, to criminal justice involvement, victimization, and even suicide. A number of strategies designed to respond to these challenges are used in many states, including: ACT, targeted peer supports, specific motivational techniques, psychiatric advance directives (PADs), and Assisted Outpatient Treatment (AOT), also known as involuntary outpatient commitment. State mental health systems must stand ready to bring a range of supports and interventions to treatment non-adherence. For a more detailed discussion of this issue, see textbox on "Non-Adherence to Treatment."

Finally, identifying which combinations of interventions work best in different locations is critical to providing comprehensive services and supports. From state to state, service structures, and administrative and financing arrangements will be different. The age composition, race/ethnicity, and poverty level of the population also will have a major impact on how services are selected and implemented. In the end, each state must find its own recipe for success.

2. Integrating Multiple Systems

Mental health services and supports typically are delivered by a wide range of providers working with different funding streams and a variety of rules and regulations. The result, in the words of the New Freedom Commission, "looks more like a maze than a coordinated system of care."[12] By contrast, a well-integrated system of care would have:

[11] Rob Gurwitt, "Breakdown," *Governing* 22, no. 1 (2008). Available at http://www.governing.com/articles/0810mental.htm.

[12] New Freedom Commission on Mental Health, *Interim Report of the President's New Freedom Commission on Mental Health* (Rockville, MD: U.S. Department of Health and Human Services, 2002). Available at http://www.mentalhealthcommission.gov/reports/Interim_Report.htm.

- Funding streams that are blended (or braided) and can be easily accessed by a range of programs;[13]
- Close collaboration among the full range of involved agencies (e.g., housing, Medicaid, addictions, criminal justice, vocational rehabilitation, education);
- Seamless transitions, especially along frequently-traveled paths such as from inpatient to outpatient care, or from homeless shelters or prisons back into the community;
- Accessibility (i.e., services that are "user-friendly"—especially for those who may have limited physical capacities); and
- Administrative and programmatic requirements that are well-aligned and designed with cross-agency coordination and integration in mind.

No single state agency has complete control over all mental health services. However, because state mental health agencies have fundamental responsibility for organizing and delivering mental health care, they must assume primary responsibility for coordinating with other agencies, even those over which they have limited control (e.g., criminal justice, housing, employment, education, and workforce development). It is especially vital that state mental health agencies coordinate with Medicaid, given its large and growing importance in financing mental health services.[14]

3. Providing Adequate Funding

Finances—both available dollars and the sources of funding—drive service delivery and program design. Effective mental health services, like other types of health services, require resources and a high-quality system of care, and therefore cannot be achieved without adequate funding.

Analyses of public funding have shown that the failure to fund mental health services adequately results in significantly greater funding being required in other systems, such as child welfare, jails and prisons, and emergency rooms, to address the consequences of untreated mental illness.

Since few states put enough money into their public mental health systems to ensure services for all—or even most—of the people who need them, these systems must routinely make decisions to preserve intensity of services for fewer people or serve greater numbers by providing fewer or less intensive services. Public mental health systems are also challenged because mental health care is "countercyclical"—the need for state-provided services rises during economic downturns and other crises.

Funding for public mental health systems comes from Medicaid and other sources such as state and local general funds. Each plays an important role in the design and delivery of services

The Role of Medicaid

Medicaid, which provides federal matching funds for every state dollar spent, pays for more mental health services than any other public or private source. Medicaid covers mental health services for (among others) low-income individuals who meet strict federal disability criteria. As a result, Medicaid is an important source of coverage for many who live with serious mental illnesses. In states that have expanded Medicaid eligibility, more people with mental illnesses are likely covered.

As a significant payer of services, Medicaid has played a substantial role in shaping public mental health systems.[15] For example, Medicaid dollars may not be used to pay for inpatient psychiatric treatment for people aged 22 to 64 in facilities that primarily serve individuals with mental illnesses. This Medicaid exclusion has helped drive the trend to downsize or close state psychiatric hospitals.

The Medicaid program allows states a great deal of latitude in determining plan design. While state Medicaid plans can include a range of im-

[13] Funding streams are "blended" when money from multiple sources is pooled together to pay for a given provider or service. A newer development is "braided" funding, in which each stream is kept separate for accounting and reporting purposes, but they are combined to pay for a package of services for a given individual.

[14] Medicaid now accounts for over half of all state mental health spending (and is projected to grow to as much as two-thirds by 2017), and yet there has been little systematic state-by-state analysis of the effect of Medicaid's growing influence on mental health service systems in terms of policy, funding, and data sharing. A preliminary examination of these issues was sponsored by SAMHSA: see James Verdier et al., *Administration of Mental Health Services by Medicaid Agencies* (Rockville, MD: Department of Health and Human Services Publication No. SMA 07-4301, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, 2007). Available at http://mentalhealth.samhsa.gov/publications/allpubs/sma07-4301/.

[15] For an overview of Medicaid coverage of mental health services and some of the key challenges in the program, see Cynthia Shirk, *Medicaid and Mental Health Services* (Washington, DC: National Health Policy Forum, Background Paper No. 66, 2008). Available at www.nhpf.org/pdfs_bp/BP66_Medicaid_&_Mental_Health_10-23-08.pdf.

portant community-based mental health services (such as case management, ACT, psychiatric rehabilitation, peer supports, etc.), Medicaid-reimbursable services vary greatly from state to state depending on what services states choose to have covered by their plans. Because of differences in available services and other program elements, people who rely on Medicaid for service coverage can have very different experiences depending on the state in which they live.

Unfortunately, current Medicaid requirements and burdensome processes can make it difficult for states to bill and get adequately reimbursed for effective services, such as ACT and peer supports. The U.S. Department of Health and Human Services could help promote recovery for people with mental illness by expediting the Medicaid reimbursement process for all direct and ancillary costs of evidence-based and emerging best practices in state Medicaid plans. Given Medicaid's prominent role in funding services, mental health leaders should advocate for a well-designed Medicaid plan with policies and services that benefit persons living with serious mental illnesses.

The Role of Non-Medicaid Mental Health Funding

Non-Medicaid mental health funding, such as state and local general funds, plays a vital role in public mental health systems, as it pays for most state hospital care and provides a critical community safety net for persons in crisis or in need of other care. These funds are used to serve persons with serious mental illnesses who are not insured, who have exhausted private coverage, or who are not eligible or are awaiting eligibility for Medicaid.

Because the Medicaid program is limited in scope, non-Medicaid dollars provide important services and supports that are either reimbursed inadequately by Medicaid or not reimbursed at all. Non-Medicaid dollars, when adequate, offer the flexibility needed for comprehensive supports and, importantly, enable the development of new and innovative programs that will become the best practices of tomorrow.

Given the scarcity of resources for public mental health services, it is particularly important that state reimbursement policies and incentive structures support those services proven or that show promise to promote the health and well-being of individuals living with mental illnesses. As a recent review of financing in the behavioral health industry noted:

> A statement of values, a strategic plan, research on evidence-based practices, and even regulatory efforts are critical, but they cannot overcome the reality that what is paid for is what will be provided. Frequently, what is paid for well or easily, or with a high reimbursement rate, will have more influence on which services are provided and in what manner they are provided than the professional standards or the non-financial actions of system leaders and stakeholders.[16]

Much of the cost of care for persons living with serious mental illnesses is shifted onto public systems when private coverage is exhausted and when the private sector fails to provide equitable, timely, and effective mental health treatment.

To minimize such cost shifts and promote earlier intervention, state laws should ensure equal coverage (parity) of mental health and substance use disorders in all public and private health plans.[17] States should also ensure important patient protections such as requiring adequate numbers of specialty providers, assuring timely and appropriate access to care, and covering evidence-based interventions for serious mental illnesses.

4. Focusing on Wellness and Recovery

Mental and physical wellness are strongly linked. Studies have documented that individuals with serious mental illnesses have a higher risk of medical problems such as diabetes, hypertension, and heart disease, and die decades younger (on average) than their counterparts in the general population.[18]

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[16] American College of Mental Health Administration (ACHMA) Workgroup, "Financing Results and Value in Behavioral Health Services," *Administration and Policy in Mental Health* 31, no. 2 (2003): 85. Available at www.acmha.org/publications/FinancingPaperFinal5-16-03.pdf.

[17] Mental health insurance "parity" means that insurance plans must treat mental illnesses and medical and surgical services equally in terms of annual and lifetime limits, co-payments, coinsurance requirements, deductibles, out-of-pocket expenses, frequency of treatment, number of visits, days of coverage, or other limits on the scope and duration of treatment.

[18] Joseph Parks et al. (eds.), *Morbidity and Mortality in People with Serious Mental Illness* (Alexandria, VA: National Association of State Mental Health Program Directors (NASMHPD) Medical Directors Council, 2006). Available at http://www.nasmhpd.org/general_files/ publications/med_directors_pubs/Technical%20Report%20on%20Morbidity%20and%20Mortaility%20-%20Final%2011-06.pdf.

Many factors contribute to this phenomenon, including the side effects of many antipsychotic medications (e.g., obesity, insulin resistance, and hypertension), the use of medications without adequate monitoring, high rates of smoking, and reduced physical activity and fitness levels among people with serious mental illnesses. Having a mental illness can also undermine self-care and the ability to follow treatments, including substance abuse treatment.

There are also system-based reasons why people living with serious mental illnesses suffer from poorer health. For example, in mental health settings, general medical problems are often under-treated because:

- Many of the clinicians and organizations involved specialize in mental health care, and coordination with general health care is inadequate;
- The ability to measure and improve the quality of care (e.g., by using electronic health records) is less developed in mental health systems; and
- The mental health workforce often includes staff without professional certification and/or who have had minimal training.

At the same time, in primary care settings, mental health problems often go undiagnosed, untreated, or under-treated because a lack of training and ongoing stigma around mental illness mean medical providers may not deliver proper care. Moreover, despite the fact that many people have both mental illnesses and substance use disorders, major administrative, financial, and operational barriers still separate these two care systems.

"Recovery for me means having the ability to function at the best possible level with my mental illness in all areas of my life—specifically in all physical, social, mental, and professional capacities."

— Consumer from Alabama

Given the proven links between physical and mental health concerns and outcomes, these two parts of an individual's health must be addressed together. For people with serious mental illnesses, access to effective substance abuse treatment and health-promoting activities like exercise, smoking-cessation programs, and dietary education are critically important.

High-quality health systems recognize these institutional challenges and work to bridge the many gaps between mental health care, substance abuse treatment, and primary medical care.

5. Creating Safe and Respectful Treatment Environments

Tragically, many people with serious mental illnesses have had painful experiences with the treatment system: they have been put into restraints or seclusion, coerced into certain forms of treatment, suffered abuse or assault, or generally had their concerns ignored. In some parts of the country, inpatient psychiatric treatment facilities, community treatment centers, and residential programs are unsafe and even dangerous. All of this undermines trust and one's willingness to participate in future treatment.

Just like consumers of any health care service, people with serious mental illnesses should be treated with respect and dignity; they should be informed about their medical conditions, consulted about treatment options, and play an important role in planning for their recovery. People with serious mental illnesses should also experience safe and respectful treatment environments which, at a minimum:

- Have well-trained staff and adequate staffing levels;
- Recognize that most clients have histories of trauma, and that forced interventions (which cause trauma as well as re-traumatization) are to be avoided;[19]
- Promptly investigate complaints of abuse and neglect;
- Follow a policy of sharing the findings of any investigation with the individual and family involved;
- Take immediate action to remedy problems; and
- Investigate fully and report publicly on all deaths, serious injuries, and incidents of abuse or neglect.

[19] Trauma, in this context, refers to the personal experience of interpersonal violence including sexual abuse, physical abuse, severe neglect, loss, and/or the witnessing of violence, terrorism and/or disasters. See the National Association of State Mental Health Program Directors (NASMHPD), *Position Statement on Services and Supports to Trauma Survivors* (Alexandria, VA: NASMHPD, 2004). Available at www.nasmhpd.org/general_files/position_statement/posstmb.htm; see also Kevin Ann Huckshorn, *Trauma Informed Care: Training Curriculum for Preventing Violence and Coercion, Reducing the Use of Seclusion and Restraint: A Workforce Training Curriculum for State Mental Health Agencies* (Alexandria, VA: NASMHPD Office of Technical Assistance, 2004).

6. Providing Accessible Services

The onset and diagnosis of a mental illness is, at a minimum, unsettling; more often, it is very traumatic. It is extremely important that consumers and their family members have quick and easy access to current and accurate information about mental illnesses, options for further evaluation and diagnosis, treatment alternatives, and local resources and supports.

State mental health agencies play a critical role in ensuring this information is available, both electronically and through other sources. Through the Internet, information should be searchable on all state mental health agency websites, and must quickly and easily connect individuals and families to mental health services in their communities. Since not all Americans have access to online information, mental health information must also be made available in primary health care settings, over the telephone, in schools, libraries, and through faith-based and other community-based organizations. Multiple forms of access are especially important for traditionally underserved groups and for people living in rural and frontier communities.

7. Establishing Cultural Competence

As the Surgeon General said in the 2001 supplemental report *Mental Health: Culture, Race, and Ethnicity*, culture—beliefs, norms, values, and language—play a key role in how people think about and experience mental illness, whether they seek help, the quality of the services they receive, and the kinds of treatments that may work best for them. This report, as well as the New Freedom Commission and IOM reports referenced earlier, all have documented that people from minority racial and ethnic communities have less access to mental health services, are less likely to receive these services, and often receive a poorer quality of care once in treatment.[20]

While each of these reports calls for better access to high-quality mental health services for the underserved, the New Freedom Commission specifically concludes that providing culturally competent care is an effective way to reduce disparities in treatment and outcomes. Thus, mental health systems must provide care that is sensitive and responsive to cultural differences. This means being aware of the impact of culture and having the skills to respond to a person's unique cultural circumstances, including his/her race and ethnicity, national origin, ancestry, religion, age, gender, sexual orientation, physical disabilities, or specific family or community values and customs.

> *"In the world of mental health, recovery doesn't mean getting healed of the illness but being able to cope in the world—holding a job, having opportunities..."*
>
> — Family member from Arizona

A number of state mental health systems have made great strides in increasing their cultural competence, using evidence-based practices to bring cultural awareness to their workforce training, service delivery, written materials, and other resources.

8. Building Consumer-Centered and Consumer- and Family-Driven Systems

Historically, people with serious mental illnesses have had little input into the services they receive. Moreover, their families' views often have been discounted, even though family members are often the primary caregivers. Negative experiences with the treatment system ultimately undermine trust and participation in treatment. A mental health system that is truly consumer-centered and consumer- and family-driven requires the meaningful involvement of individuals and families in the design, implementation, and evaluation of all services. Individual needs and preferences should also drive the type and mix of services selected in individualized plans of care.

Many states and communities have tried to accomplish this by putting people with mental illnesses and their families in advisory roles. Advisory activities can help individuals and families achieve a certain level of empowerment. However, sometimes as "advisors," their feedback can be easily ignored. Individuals and family members must be included on state Pharmacy and Therapeutics (P&T) committees, monitoring teams authorized to make unannounced visits in hospitals and

[20] U.S. Department of Health and Human Services, *Mental Health: Culture, Race, and Ethnicity-A Supplement to Mental Health: A Report of the Surgeon General* (Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, 2001). Available at www.surgeongeneral.gov/library/mentalhealth/cre/.

other treatment settings, and policy committees with real decision-making authority. A more equal partnership between people with mental illnesses and their family members, mental health administrators, and service providers is the goal.

Additional steps states should take to build consumer-centered mental health systems include: adopting high standards for certifying peer support specialists; promoting opportunities for individuals to get certified; and ensuring that peer support specialists are paid well and can be reimbursed through state Medicaid plans. Increasing the number and variety of high-quality consumer-*run* services also will help empower consumers and their families.

9. Fielding an Adequate and Qualified Mental Health Workforce

Across the country there is a critical shortage of qualified mental health personnel—from psychiatrists and nurses, to social workers and other direct service providers. Recruitment, diversity, retention, training, education, and performance are all falling short of what is needed. As the Annapolis Coalition reported in its 2007 *Action Plan for Behavioral Health Workforce Development:*

> It is difficult to overstate the magnitude of the workforce crisis in behavioral health. The vast majority of resources dedicated to helping individuals with mental health and substance use problems are human resources, estimated at over 80 percent of all expenditures. [...] there is substantial and alarming evidence that the current workforce lacks adequate support to function effectively and is largely unable to deliver care of proven effectiveness in partnership with the people who need services. There is equally compelling evidence of an anemic pipeline of new recruits to meet the complex behavioral health needs of the growing and increasingly diverse population in this country.[21]

Without a well-trained and appropriately-sized workforce, all efforts at mental health system transformation are likely to fail. To ensure there is an adequate supply of qualified mental health personnel, state mental health agencies must work with other organizations (e.g., universities and colleges, state and local workforce investment boards, state labor agencies) on initiatives such as:

- Establishing education subsidy and loan forgiveness programs for students pursuing careers in mental health;
- Promoting and providing training on the key skills necessary for working with people who have serious mental illnesses;
- Providing on-going education for mental health service professionals and paraprofessionals; and
- Developing competitive salary and benefit structures for employees working in mental health services.

Finally, people living with mental illnesses and their families are *de facto* members of the mental health workforce, providing an enormous amount of self-care, peer support, and care for loved ones. In addition, they have a unique capacity to educate the formal members of the mental health workforce about the experience of illness, treatment, and recovery. Strengthening the ability of consumers and families to assume care-giving and advocacy roles is therefore critical, and can be accomplished by providing them with education about illnesses; training in self-management techniques; and strategies for navigating systems of care, among other things.

10. Ensuring Transparency and Public Accountability

A transformed mental health system must be both transparent and accountable to the people it serves and to the public at large. It therefore must be able to measure, analyze, publicly report on, and improve the quality of care it delivers.

It is also critical that these measures and reports be standardized across states, a process that requires federal direction and leadership. The IOM recommended in 2006 that the U.S. Department of Health and Human Services[22] convene multiple stakeholders as part of a National Quality Forum "for the purpose of reaching con-

[21] Michael A. Hoge et al., *An Action Plan for Behavioral Health Workforce Development: A Framework for Discussion* (Rockville, MD: Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services, 2007). Available at www.annapoliscoalition.org.

[22] This federal department oversees the Substance Abuse and Mental Health Services Administration (SAMHSA), the National Institute of Mental Health (NIMH), the Centers for Medicare & Medicaid Services (CMS), and the Agency for Healthcare Research and Quality (AHRQ).

sensus on and implementing a common, continuously improving set of mental health and substance-use health care quality measures for providers, organizations, and systems of care" (IOM, 2006, p. 14).

The IOM goes on to recommend that these measures be analyzed and displayed "in formats understandable by multiple audiences, including consumers, those reporting the measures, purchasers, and quality oversight organizations" (IOM, 2006, pp.14-15). The IOM also recommends that measures:

> [...] include a set of mental health/substance use "vital signs": a brief set of indicators—measurable at the patient level and suitable for screening and early identification of problems and illnesses and for repeated administration during and following treatment—to monitor symptoms and functional status. The indicators should be accompanied by a specified standardized approach for routine collection and reporting as part of regular health care. Instruments should be age- and culture-appropriate. (p.15)

The development of standardized, valid, and reliable person-level outcome measures to assess treatment results is critical to tracking performance and quality improvement in state public mental health systems. Ideally, measures such as these will become available and serve as the foundation of future editions of *Grading the States*.

New Challenges Ahead

In NAMI's view, these 10 elements are the pillars of a transformed state public mental health system. The broad values they represent work in different settings and will remain relevant over time. As we look ahead, we also see new challenges on the horizon:

Scientific Advances

We are witnessing a near revolution in basic neuroscience that is challenging our understanding of mental wellness and illness; redefining the boundaries between the fields of neurology, psychiatry, and psychology; and pointing the way to completely new interventions that promise to prevent, treat, and even cure some mental disorders. These new discoveries will shift the landscape of state- and community-based mental health services in ways we can only begin to predict.[23]

Emerging Populations in Need

As wars in Iraq and Afghanistan continue, increasing numbers of veterans, including members of the National Guard, are returning with serious mental illnesses that require substantial assistance for them and their families as they transition back home. This emerging population of mental health consumers will challenge state mental health systems in new and unpredictable ways.

"Recovery means being able to manage my illness to the point that you don't know I'm schizophrenic unless I tell you."

— Consumer from Texas

Also, as states and communities make real efforts to increase their cultural competence, new populations will continue to enter the mental health system (racial/ethnic minorities, non-English speaking individuals, people with hearing impairments, people living in rural and frontier areas, etc.). States must be prepared to meet the needs of all these groups.

Technological Developments

Innovative technologies such as telemedicine, electronic health records, computer-based clinical decision-support systems, and computerized provider order entry (electronic prescribing systems) have the potential to greatly improve access to high-quality mental health services.

The mental health care system must be fully included as a National Health Information Infrastructure (NHII) begins to take form. From the earliest stages of this new initiative, the interests of mental health consumers must be recognized. For example, consumers' specific needs around data and privacy standards and electronic health records must be taken into account; and community and regional mental health networks must be also integrated within the larger NHII.

[23] For a discussion of these issues, see Laudan Aron and Carl Zimmer, *The New Frontier: Neuroscience Advancements and Their Impact on Nonprofit Behavioral Health Care Providers* (Milwaukee, WI: Alliance for Children and Families, 2005). Available at www.alliance1.org/home/neuroscience_full06.pdf.

Comprehensive Services and Supports

Access to Prescribers and Medications

Medications—and someone to prescribe them—are an essential part of successful treatment. According to the National Institute of Mental Health, individual patients need more, not fewer, choices. Unfortunately, in an attempt to control prescription drug costs, many state Medicaid programs have adopted policies that limit access to psychiatric medications, especially newer "second-generation" or "atypical" antipsychotics. These policies include requiring prior authorization, requiring or encouraging the use of generic medications, imposing higher co-pays, limiting the monthly number of prescriptions covered, requiring that enrollees fail on one medication before another is prescribed ("fail-first" policies), and developing a preferred drug list (PDL) to promote the use of less expensive drugs. All of these can lead to poorer health outcomes (including death), increased emergency room visits, hospital care, and institutionalization. In a high-quality mental health system, decisions about medications are based on an individual's needs and preferences and the best available clinical judgment.

Acute and Long-Term Care Treatment

While advances in mental health treatments (and the provision of comprehensive community-based supports) may reduce the number and length of inpatient hospitalizations for many people with serious mental illnesses, it is clear that there will always be a need for these inpatient services. Acute care beds, group homes, and other 24-hour residential programs for people who require continuous care on a long-term basis must be available at sufficient levels.

Yet, across the country, there are significant shortages. States seeking to reduce costs by closing, consolidating, or reducing state hospital services are simply shifting the burden to other systems. Neither nursing homes nor unlicensed and unregulated board and care homes are effective or appropriate treatment options. Instead, states must provide innovative, high-quality and accessible inpatient options, including quality state hospital settings.

Affordable and Supportive Housing

Many people with serious mental illness have limited incomes and need access to decent and affordable housing. Some also need "supportive housing," which combines affordable housing with support services such as job training, life skills training, alcohol and drug abuse programs, and case management. The combination of housing and support works well for people with serious mental illnesses whose housing is at risk and who have very low incomes. Without supportive housing, many will end up in (and often overwhelm) much higher-cost and less appropriate settings like jails, hospitals, mental health facilities, and homeless shelters.

Assertive Community Treatment (ACT)

The most studied and widely used intervention for people with serious mental illnesses who require multiple services and highly intensive supports is known as Assertive Community Treatment (ACT). An evidence-based, outreach-oriented, service delivery model using a 24-hours-a-day/seven-days-a-week multi-disciplinary clinical team approach, ACT provides comprehensive, individualized community treatment (including substance abuse treatment, housing and employment support) to individuals in their homes, at work, and in the community. ACT teams consist of a psychiatrist, mental health professionals, psychiatric nurses, peer specialists, vocational specialists, substance abuse specialists, and administrative support.

Consumer Education and Illness Self-Management

Illness management and recovery programs educate people about their diagnoses and treatment options so they can make informed decisions and manage their illnesses more effectively. These programs teach strategies for minimizing symptoms, preventing relapse, and using medication effectively. They also cover topics such as building social supports, setting and achieving personal goals, and getting needs met in the mental health system.

Crisis Intervention and Stabilization Services

The mental health care system must be able to respond to people in crisis in a timely and compassionate way. In many places, law enforcement personnel take on this role, often with little or no training. By contrast, in high-quality mental health systems, crisis intervention and stabilization services are available around the clock. These include telephone crisis hotlines, suicide hotlines, consumer-run warm-lines, crisis counseling, crisis outreach teams, crisis respite care, crisis residential treatment services, and first responders spe-

The Importance of Data

A key component of the transformation agenda NAMI envisions is that decision-making be consistently driven by reliable data. We believe this will not only increase accountability but will improve results. However, little systematic reporting—especially reporting that allows state-by-state comparisons—has been available.

NAMI stepped into this vacuum in 2006 with the first *Grading the States* report, and remains committed to tracking progress towards our vision of a treatment system that is accessible, flexible, and promotes continuity of care, while paying for only those services that work.

This 2009 report takes an important step in that direction: it begins to track outcomes in addition to simply recording the availability of various services. For exam-

cially trained to deal with mental health emergencies in safe and appropriate ways, such as through the CIT (Crisis Intervention Team) program.

Family Education

Family education programs are designed to educate family members about the mental illness of a loved one, and help them work effectively with that family member, as well as with any professionals who are involved, to prevent relapse and promote recovery. Through relationship building, education, collaboration, problem solving, and an atmosphere of hope and cooperation, family education helps families and supporters learn new ways of managing mental illness, reduce tension and stress within the family, and support and encourage each other.

Integrated Treatment of Co-occurring Disorders

Research shows that integrated approaches to treating people with co-occurring mental illness and substance abuse disorders produce better outcomes. The best known approach is integrated dual diagnosis treatment (IDDT), an evidence-based program that provides treatment for both illnesses at the same time and in one setting. Many states and communities understand that co-occurring disorders should be the expectation, not the exception.

Jail Diversion

One of the most visible and tragic indicators of how poorly our mental health care system is performing is the number of people with serious mental illnesses in our nation's jails and prisons. Many are there for misdemeanors or minor non-violent felonies, yet their mental illness may end up prolonging their stay. Jail diversion programs (as well as mental health courts and reentry programs) bring together the criminal justice and mental health systems to decrease the incarceration of people with mental illnesses. By linking people with mental illnesses with appropriate services both prior to, and following, an arrest, these programs short-circuit the usual law enforcement and criminal court processes. They have multiple benefits, including improving public safety, reducing burdens on law enforcement and corrections, and facilitating positive treatment outcomes for individuals.

Peer Services and Peer-Run Services

People living with serious mental illnesses are a growing and important part of the mental health workforce. They partner with mental health professionals on teams that provide day-to-day services (e.g., in ACT or certified clubhouses) and work on the design and administration of many programs. They may also serve in executive leadership positions. Peer-*run* programs, which are independent, autonomous programs controlled by, and accountable to, mental health consumers themselves, are gaining in prominence. These programs can serve many purposes in a community including leading advocacy or community education efforts; making drop-in centers, employment assistance programs, or recreation/arts programs available; providing crisis prevention or respite services; conducting homeless outreach or housing work; and offering peer-to-peer case management, companionship, counseling, and support.

Supported Employment

"Supported employment" is an evidence-based approach to helping people living with serious mental illnesses find and keep competitive employment. It encourages people to work within their communities and promotes successful work, social interaction, and inclusion. In contrast to traditional vocational rehabilitation, which generally begins with job training and moves to job placement when the person is "job ready," supported employment follows a "place and train" model that gives working participants job coaching, transportation, specialized job training, and continuous follow-along supports.

[24] A clubhouse is a structured rehabilitation program focusing on developing vocational skills. Clubhouse participants or "members" are involved in making decisions and in the day-to-day operations of the clubhouse. Many clubhouses have paid staff members who are people with serious mental illnesses. The International Center for Clubhouse Development (ICCD) oversees certification of clubhouses that follow the "Clubhouse Model" pioneered by Fountain House in New York City. See www.iccd.org for more information.

ple, whereas in the 2006 report we asked whether a state had a program to reduce seclusion and restraints, this time we asked for data on reductions in seclusion and restraints, and whether these data are shared regularly with the public.

With this kind of information, NAMI can begin to assess the actual quality of state mental health systems, and determine their potential for improvement. We are also able to make a number of specific, strategic recommendations. For example, while no one system, agency, or individual is authorized to make *all* decisions about mental health care, we find that ultimate ownership of—and accountability for—results must be firmly lodged in a single organization. NAMI believes the state mental health agency and its commissioner should play that role. The full set of NAMI's recommendations can be found in Chapter 4.

Perhaps most important, the data in this report can help build the political will that is desperately needed to move the nation's mental health care system forward. NAMI hopes it will drive governors, legislators, agency directors, and other leaders to finally do what needs to be done.

Chapter 2 describes NAMI's approach to assessing state mental health systems: why this is so important, what data are needed to accurately measure a state's performance, and what data are currently available instead. Chapter 2 also describes how NAMI used available data to grade state public mental health service systems.

KANSAS MENTAL HEALTH COALITION

.....Speaking with one voice to meet the critical needs of people with mental illness

SAVE MONEY, IMPROVE LIVES: PRESERVE OPEN ACCESS TO MENTAL HEALTH PRESCRIPTION DRUGS

Background:

Kansas is noted for having among the best state statutes related to medication for mental health conditions. KS 39-7,121 b. is lauded for specifically exempting mental health prescription drugs from prior authorization or a preferred drug list. These mechanisms are structured to reduce utilization (and hence, ostensibly, expense) by listing which drugs can be prescribed to patients, and/or by setting up administrative steps that patients and/or their doctors must take to get the medication that works well for them. The lists, while nominally based on clinical judgment, are generally based on cost, as the state expects to get its savings via better pricing from the manufacturers. Commonly, the more expensive drugs—usually the newer, better tolerated ones, with less side effects and thus greater patient compliance—are more likely to be restricted.

Countless studies, and the experience of other states, has clearly and repeatedly demonstrated that preserving full access to the complete range of medications used to treat mental health conditions saves money—both in Medicaid and in the State General Funds required to match it. Conversely, a plethora of data, across numerous states, has shown that restricting access to these medications drives up costs, exponentially. For example:

- Restricted access to medication through PDLs in Louisiana increased Medicaid costs 4.1%.
- When California forced patients with mental illness to switch to cheaper medication, it cost the state $6,000-$8,000 (per person) MORE due to increased hospitalizations.

The risk of increased hospitalization (with resultant higher costs) is not inconsequential, and generally is a result of discontinuation of medication treatment, and relapse and decompensation, which can happen in as little as a few days.

-One study demonstrated that implementation of a PDL produced 82% higher odds of treatment discontinuation or noncompliance.
-Another study found that 22% of patients in a Medicare prescription drug benefit program discontinued or temporarily stopped medication because of restricted coverage or management issues. Those patients were 8 times more likely to have an emergency room visit
-A California study of Medicaid patients with schizophrenia showed that discontinuation of treatment for as little as 1 to 10 days, doubled the risk of hospitalization. (An 11-30 day gap tripled the risk, and a gap greater than 30 days quadrupled the risk.)

Given that inpatient hospitalization costs range from $428 to $1,000 per person, per day, in Kansas, to maintain open access is prudent fiscal policy. As an example, one week of hospitalization ($15,554) for a person with schizophrenia made necessary by the psychotic break due to the unavailability of a PDL drug costs as much as maintaining that person on a newer antipsychotic medication for one year ($15,000). Institutional costs avoided by medication therapy are about $73,000 a year, per patient.

Moreover, a significant percentage of patients who discontinue medication and experience relapse end up in jail or correctional settings, a cost of roughly $23,000 per year that is borne entirely by State General Funds.

For many mental health consumers, like patients with other chronic diseases, medication is a foundational element of recovery, which helps the symptoms, makes the illness "manageable" and allows for optimal functioning and quality of life. Access to the full range of medications, including the newest, most tolerable and most effective, is a crucial component of successful treatment and recovery. Continuity is generally essential to success in treatment. Continuity of medication is increased by preserving open access and results in a 65% decrease in inpatient costs, a 55% decrease in emergency costs, and an overall savings of $166 per patient, per month. These savings translate into recovery which enables children with mental illness to remain in their homes, to attend school, and to graduate; adults to get and keep jobs, rent or purchase homes, pay taxes, and contribute to their communities; and families to stay together and care for one another.

What is Being Done in Kansas?

Efforts were made in the last legislative session by the now-defunct Kansas Health Policy Authority amend KS 39-7,121 in order to enable them to institute a Preferred Drug List. The legislature wisely rebuffed this attempt.

Kansas has, in the past, been among a select and growing number of states that have instituted a Behavioral Pharmacy Management System as a mechanism to both control costs and improve patient safety. This program, which targets providers who are prescribing unusually high numbers or dosages of medication, or who otherwise are prescribing outside of best practice guidelines, was largely dismantled by KHPA in 2010. This program has the ability to not only provide clinical education and guidance to assist physicians and others prescribing medications for mental health, but the ability to also restrict prescribers who fail to explain or change prescribing behavior. As such it has tremendous power to not only improve patient care, but also to control increasing costs of medication Other states have saved as much as $7 million/year, by robustly using this program; when in effect in Kansas it saved $1.7 million/year) This program is available for $500,000, 75 percent of which can be funded by federal Medicaid funds. The $125,000 state share need not be new revenue. This amount is readily available through improved efficiencies that can result from e-prescribing and maximizing generic drug rebates by KHPA/KDHE.

LEGISLATIVE CALL TO ACTION –

-Recognize that cutting prescription drug costs upfront won't result in savings overall. Savings from prescription medicine restrictions in 47 Medicaid programs nationwide were offset by increased spending elsewhere in the system, particularly when it came to physician services and inpatient hospital care.

- Instruct KHPA/KDHE to seek and secure federal Medicaid match funds to reinstate the Behavioral Pharmacy Management Program. This will provide a means to control the overall costs of mental health medications WITHOUT increasing costs in other parts of the Medicaid or SGF budget

- Continue to support, and block any efforts to overturn or undercut KS 39-7,121 b. This statute is the exemption for mental health prescription drugs from a prior authorization or a preferred drug list, which protects patient's rights to choice in treatment, enables recovery and saves money.